



Peer-Reviewed Original Research

Use of Social Media as a Virtual Community and Support Group by Left Ventricular Assist Device Patients

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Abstract

Background

Left ventricular assist device (LVAD) patients may benefit from participating in a social support group; however, several factors may limit the availability of these communities. Alternatively, online social support communities may be more accessible for LVAD patients. No studies have examined patterns and reasons for health-related social media use among people with LVADs

Methods

An online survey of patients actively participating in LVAD social media groups was conducted using both multiple choice and open-ended questions.

Results

Thirty-nine participants (65% male) completed the survey. Participants' reasons for weekly engagement in online communities were to seek (69.2%) and offer (66.7%) advice, seek (43.6%) and share (71.8%) coping strategies, seek help (48.7%) or help others (64.1%) solve LVAD problems, and offer general social/emotional support (74.4%). Negative aspects from involvement in a virtual community included an excessive focus on fear/negativity (26.3%) and confusing or misleading information (21%). Most felt supported (100%) from involvement in the virtual community and believed that the information/advice received was helpful (94.6%) and accurate (100%). A significant minority (41.7%) reported that it was easier to get medical advice from Facebook groups than from their health care providers.

Conclusions



LVAD patients use social media to exchange information/advice, share coping strategies, and work with others to solve LVAD problems. Benefits to participating in these groups exist; however, the degree to which they are utilized for medical advice, instead of consulting a health care professional, highlights the importance of a trusting relationship between practitioners and LVAD patients.

Keywords

social media, LVAD, support system, virtual community, internet, online

Background

Heart failure is a global health concern, with 41 million worldwide¹ currently living with the disease. In the US alone, 5.1 million adults live with heart failure² and, current projections estimate that greater than 8 million will be affected by 2030.³ Left ventricular assistive device (LVAD) implantation is an increasingly common surgical intervention to reduce mortality and improve quality of life for patients with advanced heart failure.⁴ LVADs may be implanted as destination therapy, bridge to transplant, or bridge to decision⁵⁻⁷. As of February 2015, over 27,000 LVADs have been implanted worldwide.^{8,9}

LVAD implantation recipients are required to possess information and skills that allow them to successfully engage in a variety of self-care activities including driveline management, medication compliance, diet adherence, and monitoring of pump parameters.¹⁰ In addition, having an LVAD has considerable implications for quality of life; patients have reported fear and anxiety due to the awareness that they depend on an LVAD for survival⁴ and lack of control over their daily lives.¹¹ Patients also report a need to develop trust in the LVAD, and confidence in their ability to care for it successfully.¹²

Access to resources for information and emotional support is critical for patients who engage in complex self-care activities for their LVADs. Like many other patients dealing with a chronic illness, LVAD patients may benefit from belonging to a community of similar individuals. Such communities may provide opportunities for patients and their caregivers to ask questions, share personal knowledge, and offer support to others in similar circumstances.¹³⁻¹⁵ However, geography and limited numbers of LVAD patients may present a barrier to obtaining information, particularly for those who live in isolated rural communities. Problems with accessibility of information and support can be offset through the use of the Internet. An estimated 51% of adults with chronic illnesses in the US use the Internet to obtain information about diagnosis and treatment of specific illnesses.¹⁶ In addition, use of social media via the Internet is increasingly common for people with chronic illnesses to locate and communicate with a virtual community of people who have similar illnesses.¹⁷⁻¹⁹ A growing number of virtual communities for LVAD patients and their caregivers exist on the social media site Facebook. Despite the increasing prevalence of these communities, little is known about social media use among people with LVADs.



The purpose of this manuscript is to describe preliminary findings from a survey that examined patterns and reasons for health-related social media use among people with LVADs and to discuss implications of the study findings for health care delivery and providers. The main research questions guiding this study were:

- 1) What are the characteristics of LVAD patients who use LVAD virtual communities?
- 2) What are the primary reasons that LVAD patients use LVAD virtual communities, and how often do they use these virtual communities?

Methods

Design and Sample

This study involved a mixed methods design incorporating a semi-structured survey instrument that had additional open-ended questions. As such, a descriptive cross-sectional analysis of the survey questionnaire was enriched by supporting qualitative data. A convenience sample of participants was obtained via messages including a link to the survey posted on 3 different LVAD groups on the social media site, Facebook. Group members were also allowed to cross-post the link to additional groups. Inclusion criteria were: having either a BTT or DT LVAD implant, and current participation in a LVAD virtual community. Exclusion criteria were inability to read and write English, and less than 18 years of age.

Instrument

The quantitative portion of this study used a 13-item Likert-scale survey focused on reasons and frequency of virtual community engagement and a 5-item Likert-scale survey focused on opinions about the information they obtain from other members of the virtual community. Both were developed by the research team for use in this study based on adaptations of a validated survey used in a study of family caregiving in chronically ill adults.²⁰ Response choices for reasons and frequency of use were 0 = "Never," 1 = "Less than once a week," 2 = "1 – 3 times a week," 3 = "4 – 6 times a week," and 4 = "Daily." Response choices for opinions about the information obtained from social media were 1 = "Strongly disagree," 2 = "Somewhat disagree," 3 = "Somewhat agree," and 4 = "Strongly agree." The qualitative portion of this study included eight open-ended questions focused on perceptions of barriers and facilitators to use. Demographic information was also collected.

Data Collection

Survey data were managed using Research Electronic Data Capture (REDCap) tools, a secure, web-based application designed to support data capture for research studies, providing: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated



export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources.²¹ Links to access the survey were posted on each LVAD community site between September 1 and October 13, 2014. The sponsoring University's Medical Institutional Review Board approved all study procedures prior to recruitment and data collection. Participation in the survey indicated implied consent. Procedures to ensure participant anonymity were followed throughout the study duration.

Data Analysis

Thirty-nine participants meeting the inclusion criteria completed the survey. Frequencies and percentages were used to present demographic information and information on the categorical and ordered categorical items in the survey. Potential gender and age differences in reasons for and frequencies of use of online groups were examined using chi-square analyses. Means with standard deviations were used to describe scale scores on the survey. Frequencies and percentages were also used to describe specific opinions regarding the use of virtual communities. All statistical analysis was conducted using SPSS (IBM Corp., Armonk, NY).

Results

Participants were primarily male, white, middle aged and older, and highly educated. The majority of participants were recipients of a Heartmate II, had been implanted for greater than 1 year, and did not have an in-person support group in their area (see Table 1). There were no significant gender differences in any of the demographic characteristics of the sample.

Table 1 Demographic Characteristics of Respondents

	N (%)
Gender	
Male	25 (64.1)
Female	14 (35.9)
Ethnicity	
White	32 (82.1)
Non-white	7 (17.9)
Age	
20 – 39	2 (5.1)
40 – 59	15 (38.5)
60 +	22 (56.4)
Marital Status	



Single	7 (17.9)
Married	25 (64.1)
Divorced	7 (17.9)
Education	
High School or Less	11 (28.2)
Some College	17 (43.6)
College Graduate	11 (28.2)
Type of LVAD	
Heartmate II	34 (87.2)
HeartWare	4 (10.3)
No response	1 (2.5)
How long have you had your LVAD?	
1 Year or Less	11 (28.2)
Greater Than 1 Year	28 (71.8)
How long does it take you to travel to your LVAD center?	
1 Hour or Less	19 (48.7)
Greater than 1 Hour	20 (51.3)
Is there an in-person support group in your area?	
Yes	12 (30.8)
No	20 (51.3)
Don't Know	5 (12.8)
No response	2(5.1)
Are You an Active Participant?	
Yes	12 (32.4)
No	27 (69.2)

Participants were quite active in the use of social media. Reasons participants provided for using social media was primarily to communicate with friends and family and to obtain information about LVADs and offer support to a person with an LVAD (see Table 2). There were significant age differences in getting information about LVADs from online groups, with a greater proportion of those aged 60 years and older reporting using online groups at least weekly as compared to those who were 40-59 years and 20-39 years (86.4% vs. 46.7% vs. 50.0%). There were no other differences in age or gender in reasons participants used online groups.



Table 2. Frequencies of Social Media Use

How often do you use social media to...?	Mean (SD) *
Get information about LVADs	2.57 (1.281)
Give information about LVADs	2.31 (1.167)
Find out if anyone else is having the same problems that you have with your LVAD	1.94 (1.194)
Share how you cope with having a LVAD	2.19 (1.221)
Ask others how they cope with having a LVAD	1.54 (1.12)
Share how you solved problems with your LVAD	2.05 (1.246)
Ask others how they solved their problems with their LVADs	1.57 (1.144)
Offer support to a person with a LVAD	2.41 (1.189)
Give information to a spouse or a family member of a person with a LVAD	1.81 (1.33)
Offer support to a spouse or a family member of a person with a LVAD	1.92 (1.402)
Provide personal entertainment (play games, watch entertaining videos etc.)	2.00 (1.586)
Communicate with friends	3.43 (0.929)
Communicate with family	3.24 (1.038)

* Means and standard deviations are based on scale scores on individual items with 0 = never, 1 = Less than once a week, 2 = 1 – 3 times a week, 3 = 4 – 6 times a week, 4 = Daily

Participants stated that the information obtained through Facebook was helpful and that it was easier to obtain than by contacting their health care providers (see Table 3). A greater proportion of females as compared to males (66.7% vs. 29.2%) reported that it is easier to use Facebook to get answers to questions than to contact a healthcare provider. There were no other differences in age or gender in opinions on the information obtained through Facebook.

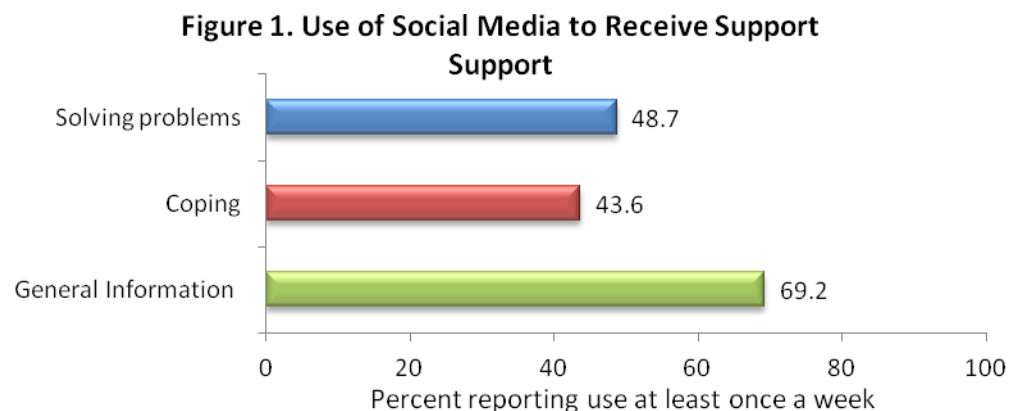


Table 3. Opinions on the Information Obtained Through Social Media

	Mean (SD) *
The information I get through social media from other LVAD patients is accurate	3.31 (0.467)
The information I get through social media from other LVAD patients is helpful to me	3.43 (0.603)
The support I get through social media from other LVAD patients is helpful to me	3.51 (0.507)
It is easier for me to use social media to communicate with other LVAD patients than to go to a LVAD group in my community	3.49 (0.804)
It is easier for me to use social media to get answers to my questions than to contact my healthcare provider (physician, nurse practitioner, LVAD coordinator, etc.)	2.11 (1.09)

* Means and standard deviations are based on scale scores on individual items with 1 = "Strongly disagree", 2 = "Somewhat disagree", 3 = "Somewhat disagree", 4 = "Strongly agree"

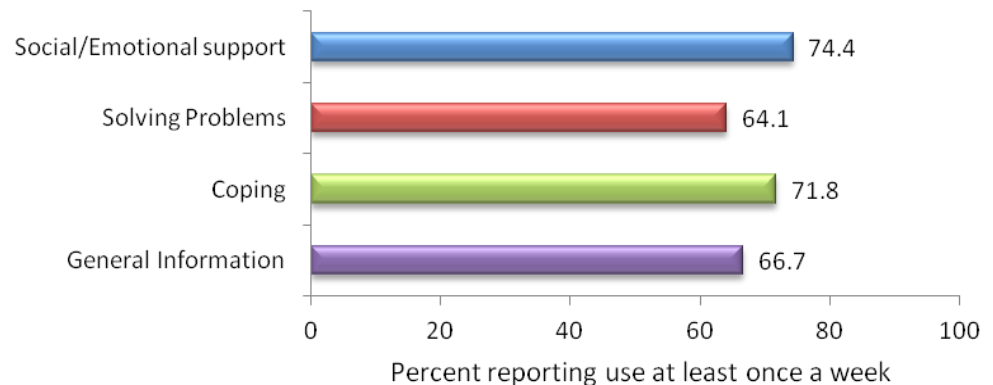
Moreover, participants specifically reported use of the virtual community support groups to both give and receive support from others. The most commonly reported ways support was given to others were by the sharing of general information and/or medical advice, sharing of coping strategies, helping others troubleshoot and solve problems with their LVAD, and providing general social and emotional support to LVAD patients and their family members (see Figure 1).



The most commonly reported ways to receive support were by seeking general information and/or medical advice, asking about coping strategies, and asking for help troubleshooting and solving problems with their LVAD (see Figure 2).

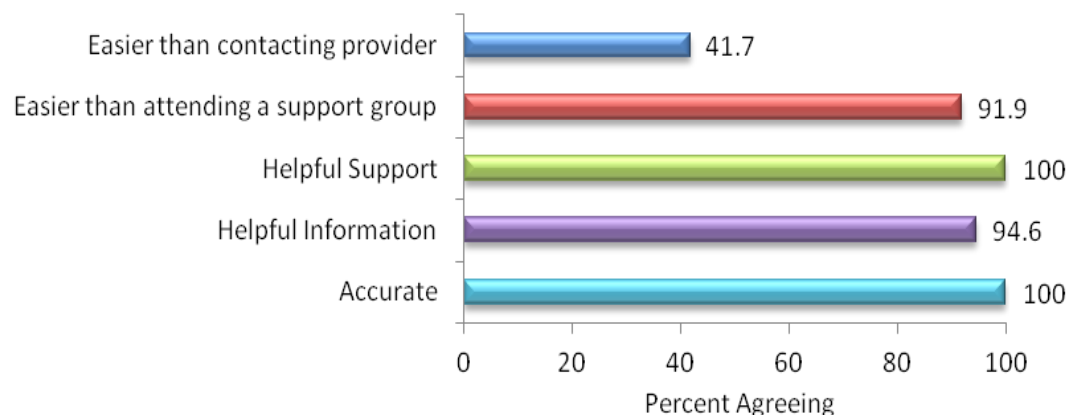


Figure 2. Use of Social Media to Give Support to Others



Although 31.5% reported that there were no negative aspects of using the social media support groups, others identified an excessive focus on fear/negativity (26.3%) and confusing or misleading information (21%) as major problems. Despite believing that confusing or misleading information was a potential problem, all respondents reported that the information they received was accurate, and 41.7% said that it was easier to get medical advice on the social media sites than from their health care providers (physicians, nurse practitioners, LVAD coordinators, etc.). A majority found the information they received from others in the group to be helpful and that participating in the Facebook group was easier than attending an in-person support group meeting. All participants agreed that the support they received from others in the virtual community group to be helpful (see Figure 3).

Figure 3. Opinions About the Use of Social Media



Users of these Facebook groups develop close relationships with one another; slightly more than half (53%) reported interacting in person with others they met through the Facebook groups. The prime reason for using Facebook support groups instead of traditional groups was physical distance from such a group (33%); and slightly more than half (53%) reported that there is no group available in their area. Many respondents emphasized feeling a sense of community by



sharing with others in similar situations. A majority of respondents reported living more than an hour away from the nearest LVAD center and shared that participation in the Facebook groups helped to remove feelings of isolation. One respondent stated, "Social Media provides a medium to communicate with people with LVAD experience from all over the world. Where I am, the LVAD population is quite small and social media really helps make you feel like part of a community."

Not all aspects of social community were seen as positive by the participants, however. Several respondents shared experiences of arguments and personal attacks fostered by the relative anonymity offered by the virtual environment that they felt would not have occurred in a face-to-face setting. "Occasionally, a fellow LVAD patient will step over boundaries and make comments or judgment on my personal life or choices that I have made without asking." One person shared an experience where someone was attempting to scam LVAD patients out of money.

Most agreed that one of the more difficult aspects was becoming attached to people from around the world who then suffer a setback and may even die. This is especially troubling for patients given that they are in similar circumstances, and a death may be more than the loss of a friend, but also a picture of what might be coming for them in the future. One respondent says, "Sometimes it can be frightening reading about people dying or having serious infections or any of the negative parts of having an LVAD. While the information is helpful, I choose to scan over these entries because I don't want to be scared all the time."

Some participants did acknowledge concerns regarding the accuracy of information provided in the virtual communities. Such information could be inaccurate or misleading as one participant noted: "On occasion one of the caregivers on our site can give inaccurate information and it is [a] challenge to try to have the new person go directly to their LVAD coordinator for specific information they need." Another problem may arise from center specific protocols that may not apply equally to patients in other parts of the world. As another participant commented, "There are no national best practices with an LVAD. Every Center has different rules ... so any information or support given is typically preceded with 'check with your center/team first.'" Hence despite participants' valuation of the support provided through the virtual communities, they acknowledged the need to verify information.

Discussion

Social media use continues to grow, with 74% of all Internet users now regularly participating in some social media outlet such as Facebook, Twitter, MySpace, or LinkedIn²². Facebook is the dominant platform, with 71% of virtual adults using its service.²² As of December 2014, that equates to 890 million users per day and 1.39 billion each month.²³ These outlets have the potential to support patients dealing with chronic illness to better cope with their illness and to take a more active role in their health.²⁴ Although social media has been used extensively as



a support mechanism in patients with chronic diseases (such as diabetes,²⁵ renal disease,²⁶ and COPD,²⁷) this preliminary study is the first known examination of the use of social media as a support system by LVAD patients.

Social support was the most commonly cited reason for participating in the Facebook LVAD groups. Studies among individuals with other chronic conditions have demonstrated similar findings for the use of virtual support groups.^{28,29} In addition to the social support aspects of these groups, our study revealed that a majority of users utilize these groups as a forum to seek and share medical information and dispense and receive medical advice. This is not surprising, as previous studies have shown that 60% of all Internet users report seeking medical information from an online/virtual source.^{30,31}

What is surprising, however, is the fact that every respondent to the survey believed that the medical advice they received from others on the Facebook groups was accurate. Virtual medical information often varies in quality and accuracy.³² This may be especially true when the information is provided by non-medical professionals. Respondents to the survey in our current study admitted that inaccurate or misleading information is a potential problem with social media. For example, a well-meaning patient passed along advice received from a physician, not understanding that it does not necessarily apply to all patients in similar circumstances.

It is equally disconcerting that almost half of those surveyed felt that it was easier to get medical information and advice from a Facebook forum than from their physician, nurse practitioner, or VAD coordinator. This may underscore a fundamental problem with healthcare delivery -- that of communication. In most medical practices, the only way to ask a question of the provider is to schedule an appointment and be seen in the clinic. This is largely a result of the way providers are reimbursed for services, with no reimbursement offered for phone or email consultations.

Additionally, many practitioners may not know how to adequately handle information patients obtain online.³³ This inadequacy may result in a paternalistic approach taken by practitioners, where patients are discouraged from seeking information themselves. While we certainly agree that a qualified medical professional is the best source of medical advice, it is important for practitioners to accept patients' online information seeking behaviors and to partner with them to verify evidence-based treatments and practices. This may be particularly true among females with LVADs who were more likely to endorse seeking information from online communities as compared to healthcare providers. For such patients, this would involve fostering the kind of trusting atmosphere where the patient feels free to discuss any topic with the provider. It may also mean increasing access to providers and making it easier for patients to contact them with questions.

A few important limitations need to be considered in interpreting the findings of this preliminary study. First, the study is based on cross-sectional survey data; and as such it is possible that participants' views could change with time, which



cannot be captured with cross-sectional designs. Future longitudinal studies may be warranted to assess the changes in opinions and usage of virtual communities for individuals with LVAD.

Second, our small sample size limited the examination of participant's responses by different sample characteristics. For example, because 90% of participants had a Heartmate II and 72% had their LVAD for longer than a year, at best our results are reflective of such populations. A more robust sample size with individuals with a variety of LVAD and durations of use could be more informative and representative of the LVAD community.

Finally, as our study was based on a convenience sample, there is the possibility of selection bias, such that those who responded to the survey are heterogeneous in their responses. However, it is important to note that although the question of location was not asked specifically, at least 1 respondent reported being from a country outside the US. The challenge of obtaining a representative sample from online surveys has been noted in other studies.^{34,35} For instance, it is difficult to identify the proper target population of those involved in LVAD online groups. It is possible that one participant might be a member of several groups and so obtaining a proper denominator for the actual sample that participated in the study is challenging. Future studies employing random sampling techniques could enhance the representativeness of respondents; this could mean also increasing the number of virtual recruitment sites. In addition, future studies can conduct surveys of the general LVAD population to determine the percentage of patients who are active in such online groups.

Conclusion

Virtual communities meet a need for social support among LVAD patients. Although there are many benefits from participating in these groups highlighted from our study findings, the degree to which they are utilized for medical advice, in lieu of consulting a health care professional, is concerning. Despite the inherent limitations of our study, we believe that our preliminary results highlight the importance of a trusting relationship between practitioners and patients and can help practitioners provide for the social and educational needs of LVAD patients. Moreover virtual communities have the potential to be sites of disseminating evidence-based best practices information for individuals living with LVADs. As a result, it may be important for healthcare providers to consider a means of incorporating themselves into online communities in order to be available when evidence-based information is required. This requires cultural sensitivity in making certain that the role of provider does not hinder the free expression within these online groups. However, future studies are required to further understand ways to engage patients using novel Internet based strategies and support systems and for healthcare providers to get involved in existing online groups.

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